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Compassionate care during withdrawal of treatment: A qualitative secondary analysis of intensive care nurses' experiences

Abstract

Background: Withdrawal of treatment is a common practice in intensive care units when treatment is considered futile. Compassion is an important aspect of care; however, it has not been explored much within the context of treatment withdrawal in intensive care units.

Objectives: The aim was to examine how concepts of compassion are framed, utilised and communicated by intensive care nurses in the context of treatment withdrawal.

Design: The study employed a qualitative approach conducting secondary analysis of an original data set. In the primary study, 13 nurses were recruited from three intensive care units within a large hospital in United Kingdom. Deductive framework analysis was used to analyse the data in relation to compassionate care.

Ethical considerations: The primary study was approved by the local Research Ethics Committee and the hospital's Research and Development services.

Findings: Compassionate care was mostly directed to the patient's family and was demonstrated through care and emotional support to the family. It was predominantly expressed through attempts to maintain the patient's dignity by controlling symptoms, maintaining patient cleanliness and removing technical apparatus.

Conclusion: This study's findings provide insight about compassionate care during treatment withdrawal which could help to understand and develop further clinicians' roles. Prioritising the family over the patient raised concerns among nurses, who motivated by compassion, may feel justified in taking measures that are in the interests of the family rather than the patient. Further work is needed to explore the ethics of this.

Keywords: Compassion; Dignity; Withdrawal of treatment; Qualitative; Secondary analysis; Intensive Care

INTRODUCTION

Withdrawal of treatment is a common practice in Intensive Care Units (ICU) across the world when continuation of patient treatment is considered futile.[1] Following withdrawal of treatment, death usually occurs within one to two hours.[2, 3, 4] Some aspects of treatment withdrawal have attracted more attention than others. The process of decision making, for example, has been explored in depth and it is recognised that a multidisciplinary approach and acknowledgement of patient and/or families' wishes is important. [5, 6, 7] In contrast, the operationalisation of treatment withdrawal has not been explored to the same extent.

The operationalisation of treatment withdrawal is what follows once a decision to withdraw has been made, and comprises the action(s) required to ensure that the agreed end point is reached in the correct way. Withdrawal is typically nurse led, guided by physicians, and involves gradual reduction in supporting treatment to achieve a gradual decline that mimics 'natural death'. [8] Clinical guidelines, in the context of treatment withdrawal advise no restrictions to family visiting the patient, privacy, removal of unnecessary monitoring and alarms, provision of medications to relieve pain and distress and withdrawal of treatments that may prolong death.[9] It is also emphasised that the management of the patient's care has to be compassionate and the actual methods of treatment withdrawal should be tailored to the patient and their family by the ICU clinicians.[7, 9, 10]

Although compassionate care is advised during treatment withdrawal, it has become apparent that compassion is difficult to define and has an intuitive nature.[11, 12] Compassion within the healthcare context was initially described as an emotion consisting of empathy and sympathy for somebody who is in pain and distress. More recent analysis, however, has resulted in a definition that is not wholly affective and, rather, comprises a cognitive and motivational component, for example "awareness of another's distress and the motivation to relieve it".[13(p3008)] Although it is difficult, perhaps, to understand compassion as an entirely non- affective state (for example, the motivation to relieve the suffering one recognises seems likely to have itself an affective component), it is generally accepted that compassion is not simply a contingent emotional response, but a state that

forms part of a moral character that can be developed and cultivated (ostensibly in an Aristotelean sense) like any other virtue.[14] In this sense, compassion can be reflected on, chosen and learned, and a person can be held responsible for the presence (or lack of) compassion in their character. That notwithstanding, the idea that compassion is not simply affective, but also cognitive and intentional is strongly supported in Papadopoulos et al.'s study with a large multi-national sample where the conscious and intentional nature of compassion was acknowledged.[15]

The complexity of defining compassion, according to some commentators, has led to the omission of the term in end-of-life strategies issued by a number of countries.[16] It has, however, also been widely accepted that lack of compassion has resulted in unnecessary suffering at the end-of-life, which has led many countries to issue further reports to advance 'compassionate care',[16, 17, 18] even in the absence of clear understanding of what compassionate care is. The difficulty raised by the challenges of defining compassion is that when we introduce the term into the context of good care there is risk that defining 'good care' as 'compassionate care' simply defers the problem of what good care ought to look like. We are still left with the substantive question of what 'compassionate care' is. 'Compassionate care' as a term has emerged recently, and compounds values and practices related to compassion.[13] A concept analysis of compassionate care has revealed a number of attributes, including "caring presence, recognising and being sensitive to other's suffering, sharing of distressing experience, connecting, spirituality, providing comfort measures and demonstrating the qualities of the Holy Spirit".[19(p323)]. A more recent analysis focused on compassion in nursing has also identified kindness, empathy and dignity as defining attributes.[20]

Dewar et al.,[21] in arguing that acting compassionately involves acting to relieve suffering in a way that is *meaningful to the recipient* suggests that compassion is a relational concept, requiring recognition and validation on the part of the receiver, and not just the belief and intention of the giver. Whilst this seems plausible, this account of compassion runs into difficulty in the specific context of withdrawal of treatment, since typically unconscious

recipients are unable to recognise or validate an act as one of compassion. When this more reciprocal aspect of the care relationship is not available, compassion may well become more difficult to enact and maintain.[22]

All this suggests that the task of understanding, defining, and therefore being able to deliver compassionate care is challenging, and particularly so in the context of treatment withdrawal. One way to improve our understanding of compassion in this context is to study the way compassion is understood and enacted by carers. The data presented in this paper were taken from a larger study that aimed to explore ICU nurses' experiences during the withdrawal of treatment. The findings from the primary study suggested that intensive care nurses were doing their best to facilitate a comfortable and dignified death following a decision to withdraw treatment.[23] This paper reports a secondary analysis of the dataset, which sought to examine how compassion was framed, utilised and communicated in the context of treatment withdrawal.

METHODS

A qualitative secondary analysis was undertaken of a dataset from a qualitative study that had explored ICU nurses' experiences of end-of-life care after a decision to withdraw treatment.[23, 24] The primary study was undertaken in the United Kingdom (UK) and participants were recruited from three ICUs within a large hospital in the West Midlands region that provides clinical services to nearly 800,000 patients every year.

It was apparent during primary analysis that compassion as a concept was ubiquitous in the data, though rarely talked about explicitly. It was, however, considered important enough to be explored further through a more focused secondary analysis involving a researcher from a different discipline.[25, 26] The broad aim, the methodology used, the rich narrative data and the involvement of the researcher who undertook the interviews in the primary study, ensured that the secondary research question could be explored within the original data.[26,27]

One of the methodological challenges on conducting a secondary analysis on a concept that emerged but was not directly investigated, is that participants might have expressed their thoughts and feelings about compassionate care differently had this been the interrogative focus of the interviews. This is possible, but arguably would not have made the data more or less authentic – rather provided a different source of insight. A developing literature on the methodology of empirical bioethics has suggested that the qualitative investigation of moral concepts is challenging because participants are rarely able to clearly articulate their views and reason when questioned directly.[28] Given that, one effective way to explore moral topics such as compassion is to engage in conversations that generate narratives from which moral commitments, conceptual understanding and reasoning can be inferred and interpreted. Thus, secondary analysis of these data have allowed us to identify narratives around compassion that arose naturally during wider discussion of withdrawal of care at the end of life, and these narratives represent the way that participants naturally talked about the subject (as opposed to in response to direct questioning). This provides different, but arguably no less authentic, insight into the way compassionate care is understood and enacted.

Ethical considerations

The primary study was approved by the local National Health Service Research Ethics Committee and the hospital's Research and Development services. This secondary analysis was a form of retrospective interpretation (tapping on an existing database to elaborate on a theme that emerged but was not fully analysed in the primary study),[29] hence we did not seek further informed consent from the participants. However, we adhered to principles of ethical secondary analysis, such as confidentiality, non-maleficence and fidelity.[29] The use of secondary analysis also meant that we maximised the value of data from volunteering participants and spared the possible unnecessary burden of recruiting participants for a new study.[30]

Participants

A purposive sample of nurses who had at least 2 years' critical care experience, and had provided care to patients and their families while withdrawing treatment was obtained for the primary study. Research nurses from participating ICUs facilitated recruitment. The sample was diverse in terms of age, gender, years of experience as a nurse and prior clinical backgrounds. Information about the study was provided to potential participants and informed consent was given prior to data collection.

Data collection and analysis

Thirteen semi-structured, face-to-face interviews were conducted by an experienced male qualitative researcher and ICU nurse (NE) who had no prior links with the participating units. A topic guide was developed based on previous research and expert opinion and was reviewed by two ICU nurses to increase accuracy and validity.[31] Participants were asked to describe what end-of-life care meant to them and reflect on situations when they had provided care to patients during withdrawal of treatment. Interviews took place at the participants' workplace and lasted between 30 to 50 minutes. The interviews were audio recorded, transcribed verbatim and checked by the interviewer for accuracy. A reflexive diary was completed by the interviewer at the end of each interview to record observations such as busyness of the unit, whether withdrawal was taking place during or before the interview, and emotional expressions by the participants which assisted with the secondary analysis. All transcripts from the 13 interviews were read and were included in the analysis only if they contained comments, thoughts or views related to compassionate care.[25]

For the secondary analysis of the qualitative data, the Framework method was used.[32] This method offers the possibility for an inductive, deductive or mixed approach.[33] The aim was to explore compassionate care, hence a deductive framework method approach was used (Figure 1), as that best allowed us to search for meaning related to compassionate care and identify different presentations of the concept that emerged in the data.

As this was a secondary analysis, 'compassion' was not explored directly during the interviews. However, the primary analysis identified compassion as a theme that warranted further investigation, and this gave rise to the secondary analysis that this paper describes. During the analysis we wanted to identify the range of practices and approaches to care that could inform our understanding of compassionate care and allow differing conceptions of compassion to arise. The data were therefore interrogated for any narratives that could be interpreted as being about compassion in the broadest possible sense. For the purpose of this analysis, then, we initially defined 'compassion' very broadly as an intentional state, which has the interest and needs of another person at its core [11]. We used 'compassion' as an organising theme through which to explore various thoughts and actions that are linked through their common goals and motivations. Whilst these goals and motivations were clearly expressed in the data, the concept of compassion itself was derived analytically. The importance of the obligation to be reflexive in the interpretive project has been particularly emphasised in the context of research into moral concepts,[34,35] and steps were taken to ensure that our own experiences and prior beliefs did not lead to our analysis merely confirming our own prior commitments.

First, both authors (an academic nurse with ICU background and a bioethicist) read the transcripts in a process of familiarisation, identified categories related to compassionate care. Indexing of the transcripts was then conducted, using the identified category we wanted to explore. A matrix was generated to chart the data from each transcript, including illustrative quotes.[33] Qualitative data management software was used to aid the analysis (NVivo). Two ICU nurses further reviewed the indexing of codes under category and sub-categories, and agreed with the findings. This acted as a form of confirmability, lending further credibility and trustworthiness to our analysis.[31]

RESULTS

Twelve out of the 13 transcripts were deemed appropriate to be included in the secondary analysis. Participants had a mean age of 37 years, 10 of them had more than 5 years of critical care experience and all of them had been nursing for more than six years. The majority were female (n=10), and one was from a non-Caucasian background. Five participants reported some specialist training in end-of-life care.

As described above, 'compassionate care' was not something that participants talked about explicitly, or could explain and define. Indeed, compassion as a term during the interviews was used only by three participants on eight occasions. Two sub-categories were identified: 'Compassion through dignity' and 'Compassion through care and emotional support to family'. The sub-categories are supported by relevant quotes by the participants and additional supporting quotes can be found on Table 1.

Compassion through dignity

Dignity was conceived as providing fundamental aspects of care such as symptom control, ensuring cleanliness and removal of unnecessary technical care during treatment withdrawal: "It is about giving the patient dignity and comfort, taking away as much of the ICU as you possibly can..." (N10). Another participant (N7) provided a more specific definition: "And what is dignity, it's pain-free and not struggling, and very little awareness."

The concept of 'dignified death' seemed to be connected to participants' own understanding of what constitutes compassionate care in the process of achieving a 'good' or desirable death. Importantly, the notion of 'dignified death' was not restricted to concerns about the immediate comfort of the patient, but incorporated wider concerns about how the death appeared to others, including the family. In this sense, 'dignity' is both inwards and outwards looking, concerned both about how the death is or would be experienced by the dying patient, and also how it is perceived and experienced by others. This was illustrated through symptom control, physical cleanliness and removal of technical apparatus:

- Symptom control

Great consideration was given to symptoms such as pain and the need to provide comfort to the patient. Rattling breathing was also identified as a common symptom occurring during treatment withdrawal, signifying a lack of comfort and was perceived to indicate distress. One of the younger nurses (N11) noted how rattling breathing was not really an issue for the unconscious and non-experiencing patient at all, but it nonetheless had to be managed for the benefit of the family who may perceive this as suffering: “I mean, for the patient, I know it doesn’t really matter if you can hear them rattling but, for the family, I think it’s really important that they don’t see that the patient is suffering.”

- Physical cleanliness

Maintaining physical cleanliness was seen as essential to a dignified death, but the reasons for this were complex and included concerns about the patient themselves, the patient’s family, and the nurses’ own feelings. One nurse emphasised that maintaining physical cleanliness is a way of demonstrating that the patient still matters. The fact that patients themselves are unconscious and unaware, and therefore cannot benefit directly, suggests that this is not done for the patient’s own benefit, but for the benefit of those who witness the dying process: “The patient has to be ultimately cared for impeccably, because the families will walk away with that memory of how they looked and they need to see that you are continuing to maintain a high standard of nursing care” (N6).

In situations where the patient’s condition did not allow for a clean body, nurses reported being distressed and considered the death undignified, as well as possibly horrifying for the family. One nurse, quite upset, recalled an event where maintaining physical cleanliness was impossible, and felt that this had a negative impact on the family’s experience: “I think he'd had, he'd actually had a liver transplant which had failed so he was bleeding out of his wound and no matter what you did to him you couldn't stop this blood coming from

everywhere. I think to his family it must have just looked like some sort of horror film really seeing that blood oozing out of everywhere..." (N9).

- Removal of technical apparatus

It appeared that compassionate care was associated with the removal of technical apparatus – which seemed to reflect a wish to achieve a less-medicalised death. It was also felt that technical apparatus was distracting for the family, who tended to focus on the equipment rather than the dying patient. A senior sister (N7) mentioned: "...perhaps we should switch off the monitor at this point, because relatives sit there looking at monitors. They are holding hands but they're not focussing sometimes". The removal of monitors/equipment was not, however, unanimously felt to be appropriate, due to the concern that the patient's family may believe that their loved one is being abandoned: "...because we don't want the relatives to think that we've suddenly gone from all support to absolutely nothing, that we're still actually watching, looking, caring for that patient ..." (N1).

Compassion through care and emotional support to family

Compassion was additionally expressed through providing care and emotional support to family members. Participants consistently emphasised the importance of family support during withdrawal of treatment: "Although we have to take into consideration the patient because that is our focus of the care, I think that the relatives' care is something that we do not necessarily talk about, but is probably a lot of the time the thing that takes more of our time" (N3).

Compassion was shown by attentive listening, providing emotional support, providing timely and relevant information and allowing extensive visiting times to family members. Notably, it was reported that sometimes this concern for the family took precedence and led to decisions that were, ostensibly, not in the interests of the patient. Specifically, it was reported that withdrawal was often delayed in order for family members to be present:

“There is always time given to people who want to bring certain family here or people who are waiting for ...Whatever the scenario, time is allowed” (N6).

However, there were also concerns raised about practices that seemed to place consideration of the family’s needs over and above those of the patient. One nurse recalled a time when a patient died alone because so much attention was being paid to family: “Unfortunately the patient passed away whilst I was not in the bed space because I was busier sorting out the family; because I remember this gentleman whose family got very complicated” (N12). The morality of delaying the withdrawal for the family’s benefit was questioned by a nurse: “That is always very difficult... I mean from the patient’s point of view, you are keeping somebody alive just for the relative’s benefit but conversely we do know or we think we know that being here at the time of death does aid the grieving process... I do feel a bit uncomfortable sometimes keeping patients going for the sake of relatives turning up” (N13).

Some participants reported that in the context of treatment withdrawal, providing what was perceived compassionate care to families often necessitated opening up emotionally and showing one’s own sadness or distress – which would not be appropriate in other settings or contexts. This kind of emotional ‘quid pro quo’ was seen as important because it humanised the interaction: “it’s okay in certain situations to let your emotions to be shown I think. It shows you’re compassionate and that you actually do care” (N8). It was also recognised that a balance must be struck between showing sufficient emotional engagement to make compassion possible, but not so much that one’s own emotional response becomes burdensome to the family. One participant described maintaining that balance in the presence of the family, and then letting everything go once the shift had ended: “I think that personality wise I probably can show empathy but without breaking down in front of them and being upset but I know I left here and I cried because it was so upsetting” (N5).

DISCUSSION

The secondary analysis of one set of qualitative data, explored comments, views and expressions of compassionate care by ICU nurses during withdrawal of treatment. Globally, compassion is regarded as an essential aspect of healthcare,[36, 37] but it is an abstract concept that is difficult to define.[21, 38] Compassionate care, within this study, was often talked about in connection with acts that aimed to maintain dignity for the dying patient, a concept closely related to compassion,[20, 21] such as symptom control, physical cleanliness and removal of technical apparatus. Compassionate care was also enacted through care and emotional support for the family.

There was concern for the patient's comfort and well-being during withdrawal which had to be addressed for a dignified death, consistent with guidelines issued in most countries.[9, 10, 39] Clear concern was also shown for the comfort and well-being of the family. For example, some participants described interventions to stop 'death rattle', a naturally occurring symptom during the last hours of life which is perceived as distressing for the family.[40] However, the morality of providing medically futile treatment for a symptom to make the witnessing family more comfortable has been questioned.[41] Physical cleanliness was associated with dignified death for participants in this study, and this is consistent with other studies.[42, 43] Maintaining cleanliness was considered demonstrative of respecting the body of the patient, and was also considered beneficial for the family who were believed to perceive it as continuation of care.

As with other studies,[1, 44] removal of technical apparatus was considered important by participants in order to create a more 'natural' environment where death can occur. This could also create an environment more conducive to compassionate care.[45] This finding highlights how this intervention can be performed for the benefit of the family, not the patient, to provide space and remove distractions.[44] However, care in ICU is so closely linked with technical care that some nurses worried the removal of technical apparatus could be perceived by the family as cessation of compassionate care, demonstrating again a concern for the family rather than the dying patient.

Consistent with Melia's findings, it was apparent that following the decision to withdraw treatment, the patient became a 'body' requiring physical care, and the family became the 'persons' needing support and towards who compassionate care seemed predominantly directed.[46] Participants explained in great detail interventions to support and care for the family, in terms of providing time, space and emotional support, and explained how they felt that this could possibly be to the detriment of the patient. Similar interventions demonstrating empathy towards the family have been described by nurses in ICUs in other countries.[47] It has to be noted that allowing space and time to the family is considered a compassionate act and has been appreciated by the families of patients dying in ICU.[48]

Participants in this study also suggested that compassionate care was enacted when they were treating patients and their families as they would like to be treated if they were in a similar situation, a principle recommended by the Charter of Compassion.[49] Supporting the family in a compassionate way included also emotional engagement by the participants who, on some occasions, had difficulty in balancing their emotions and worried that they could become a burden to the family. It is acknowledged that ICU nurses caring for dying patients provide emotional labour to support patients, relatives and colleagues.[50] The emotional work of caring is an aspect of compassionate care and needs to be acknowledged and celebrated.[21] However, it is also acknowledged that putting systems in place to manage the emotional impact of being compassionate requires a lot of effort and management commitment by healthcare organisations.[51]

Compassion was rarely mentioned explicitly by participants in this study, reflecting perhaps the difficulties in defining such an abstract concept. At the same time compassionate care, such as attending to the 'little things', 'small acts of kindness', 'going over and above' and 'emotional disclosure', [11] were clearly visible in the nurses' narratives. Nurses' compassionate acts, however, were focused mostly on the patient's family, and this might be explained, and understood, in light of the fact that the family can engage in reciprocal communication of a kind that the dying unconscious patient cannot. For some nurses it may

be arguably easier to be compassionate where that reciprocity is possible, and may be favoured because it might avoid the burnout associated with one-way compassion.[22] It also, however, creates ethical conflicts which are difficult to resolve, because a compassionate act towards the family might not always be consistent with what is best for the patient. In these cases, an element of compromise may be needed.[52]

This appears to be one of the first attempts to explore compassionate care during treatment withdrawal in ICUs. The findings from this secondary analysis demonstrate transferability since the findings can be explained and understood in the terms of existing sociological theory around death and dying, and are consistent with findings from studies across the world. Limitations include the use of secondary analysis of data from a relatively small sample size and self-selected population that could restrict the theoretical generalisability of findings. We also acknowledge that participants were not specifically asked to discuss compassionate care in the primary study hence their narratives might have been different if that was one of the original questions in the topic guide. The secondary analysis however demonstrated that compassionate care attributes as described in the literature were evident throughout their experiences, and we have further justified this approach as appropriate and providing a different, but no less authentic, source of insight. Consistent with the aims of qualitative research, this analysis did not seek to generalise, but rather to shine a light on aspects of practice that have evaded the spotlight and help us understand, and provide insight in, the phenomena under study. It is essential that further research is conducted to identify what is perceived as compassionate care by all involved in withdrawal of treatment and how to resolve the ethical conflicts that may arise.

Conclusion

This secondary analysis, by exploring the concept of compassionate care during treatment withdrawal, can provide ICU nurses and physicians with insight that might help them understand and develop their role further and consequently improve patient and family care. The findings raise important questions around the appropriate way to enact compassion in this context, and in particular draw attention to questions of who the

recipients of compassionate care ought to be. These are challenging questions of some importance, especially considering the call to increase and build compassion amongst the nursing community. If these data are any indication, there may be significant ethical tensions in end-of-life care, where the need to be compassionate to both the family and the patient could lead to dilemmas that cannot easily be resolved. Whilst this ethical question cannot be resolved in this paper, the data presented identified it as being of importance and relevance, and worthy of further investigation.

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